



# 2016-2020 COLORADO CANCER PLAN Report: Stakeholder Engagement Survey

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## BACKGROUND

Like all US states, Colorado has a statewide cancer plan—developed by cancer community members and supported by the Centers for Disease Control and Prevention (CDC)—that sets forth measurable five-year objectives with the potential to positively impact a state's cancer burden. Colorado's comprehensive 2016-2020 plan covers topics from prevention, screening, treatment and survivorship, in addition to policy and health equity. The Colorado Cancer Plan goals and objectives are intended to be a framework for collaborative efforts across the state that can empower individuals and organizations in Colorado's fight against cancer.

The Colorado Department of Public Health and Environment (CDPHE), through its Comprehensive Cancer Control Program (CCCP), previously funded the Colorado Cancer Coalition (CCC) to coordinate the process for developing and implementing the statewide cancer plan. Due to [organizational changes at the Colorado Cancer Coalition](#), CCCP assumed responsibility for leading the development of the 2016-2020 Colorado Cancer Plan in April 2015. To ensure ongoing momentum in collaborative efforts that reduce the state's cancer burden, CDPHE sought feedback from stakeholders across the state.

The purpose of the survey was to assess the needs, gaps and direction of the 2016-2020 Colorado Cancer Plan by identifying:

- the cancer community's knowledge and understanding of the plan's purpose and use.
- stakeholder priorities for the plan and their motivations for involvement.
- possible gap areas in the plan and its implementation.
- key partners and motivations for involvement.

## METHODS

An online survey was administered April 22 - May 15, 2015 to statewide cancer prevention and control stakeholders, who were identified through existing networks at CDPHE and throughout the state. Data collection occurred via Survey Monkey, a web-based survey tool. To ensure the largest and most representative sample, the survey link was emailed by the CCCP team to several individuals, mailing lists and published in the COPrevent newsletter. The survey included a combination of 15 multiple choice, scaled and open-ended questions that addressed stakeholders' experience and understanding of the plan, and provided the opportunity to offer guidance and suggestions. A total of 191 anonymous respondents completed the survey.

**Limitations.** This data collection and analysis provides a point-in-time snapshot of perceptions among Colorado Cancer Plan stakeholders who self-selected into the survey through convenience and snowball sampling. Thus, the results presented here may not fully represent the target population. The survey was also implemented during the shift from one organizing body (CCC) to another (CDPHE) during the planning stages of the Cancer Plan. This timing may have contributed to some confusion about the role and expectations of the State and should be considered when reviewing respondent feedback. Nonetheless, these data provide valuable insight for strategic planning.

## SAMPLE

**Geographic Representation.** Slightly more than one-third of respondents (34%, n=65) reported that they represented statewide interests related to cancer. The remaining two-thirds of respondents (66%, n=126) indicated that they represented single (n=72) or multiple (n=54) counties, mostly urban. Denver (29%), Arapahoe (18%) and Jefferson (14%) were most frequently selected. Only two counties were not represented in this sample: Jackson and Routt.

**Affiliation/Role.** Respondents reported widely distributed affiliations. Nonprofits (29%, n=56), hospitals/clinics (24%, n=46) and college/university (19%, n=37) were most frequently selected. Only 11% of respondents (n=21) were affiliated with CDPHE. Respondents most frequently reported their roles as current employees/professionals in the field of cancer (38%, n=72). Fifteen percent of respondents (n=29) were cancer survivors. Very few retired professional (2%, n=4) and students (1%, n=2) participated.

**Interests.** Twenty-nine percent of respondents (n=55) reported interest in all cancers, with the remainder (71%, n=136) interested in specific cancer types. Respondents most frequently reported interest in breast (35%, n=66), colorectal (28%, n=54) and lung (24%, n=45) cancers. Respondents also reported most interest in the early stages of the continuum of care, including prevention (72%, n=137), screening and early detection (59%, n=112) diagnosis and treatment (51%, n=98) and post-treatment survivorship (36%, n=69).

**Community Involvement.** Sixty-one percent of respondents (n=117) reported involvement with the cancer community for five or more years, with a handful noting involvement spanning two decades or more. 7% of respondents (n=13) reported no involvement in the cancer community. 63% of respondents (n=121) indicated that they collaborate with CDPHE in some capacity, with the Cancer, Cardiovascular Disease and Pulmonary Disease (CCPD) Grants Program (31%, n=59), the Women's Wellness Connection (28%, n=53) and Tobacco Programs (23%, n=48) most frequently reported. Only 35% of respondents (n=66) reported current or previous involvement in the Colorado Cancer Plan, though 18% (n=35) were not sure.

## KEY FINDINGS

Key findings are reported below for primary areas of interest examined in the survey. Tables showing the distribution of responses for each question are provided in the accompanying data summary.

### CDPHE should facilitate the implementation of the statewide cancer plan.

Most respondents (62%, n=119) identified CDPHE as the preferred organization to facilitate the implementation of the cancer plan, with the remaining 38% divided between universities (16%, n=13), nonprofits (10%, n=19) and other (12%, n=22).

*The State Health Department should be able to convene the organizations that should be involved and also understand the nuances for getting the plan to the point of implementation. At that point have the community actually implement it.*

*The state department of health has a mandate to promote and protect the health of all Coloradans. While working with everyone is necessary the state should not defer leadership roles to other organizations. They should make this a priority.*

Respondents recognized the complexity of this process and noted the value and need for actively engaged stakeholders at all stages.

*I believe this is a multi-level task with many branches of support needed. Due to funding and support this should be split between State and Non-Profit in an effort to work on promoting effective team collaboration to reach the highest impact.*

Even respondents who selected an alternate organization to lead the implementation still valued the role of CDPHE as an “active partner” and “oversight body” with the resources and structure to administer the process.

*[CDPHE should] Lead the effort in getting a solid, committed team on board to finalize the Plan and have them ensure that there is STATEWIDE buy in.*

*Ultimately [CDPHE should be in] the leadership role, but with other types of organizations on the leadership committee.*

### Stakeholders’ motivation and involvement may depend on their understanding of the cancer plan and how relevant it is to their professional and personal interests.

Better alignment with stakeholder interests and increased understanding (via improved communication) about the plan is needed. Respondents repeatedly reported the need to understand the cancer plan’s relevancy to their daily work. Buy-in depends on how well the plan meets individual’s professional needs.

*To make it more useful to me in my work than it has been in the past and to better understand how to incorporate it into the work I would like to be doing. Also because I think I [would] be a positive influence on the plan for the consumer sector.*

*Knowing that it has value or relevance to what I and our clinical team already do at our Cancer Center. Few of my colleagues even know it exists; none have ever found it necessary to review.*

Respondents without previous involvement in the Cancer Plan were less likely than their previously involved peers to indicate interest in involvement, although several respondents new to the cancer plan did express interest in involvement. (See Figure 18.)

### Partners should represent a wide array of interests and regions.

Respondents commented about the need for non-urban/non-Denver regions to have a voice at the table though some suggested that passion and motivation was equally important. A diversity of expertise across multiple sectors is also essential. Respondents suggested numerous individuals and organizations as candidates for leadership (see Q12 responses in the Appendix).

*I think you need cancer leaders throughout the state not just Denver.*

*We also need to identify people from other parts of the state, but I'm unfamiliar with those folks. Specifically, Colorado Springs, Grand Junction, and Durango. If possible, engage folks from other areas as well: SE Colorado, San Luis Valley, Vail and/or Glenwood, Pueblo.*

### Education, communication and outreach about the Cancer Plan are needed.

Perceptions were generally positive about the usefulness of the Cancer Plan; however, increased and consistent communication is desired and needed, both to educate the cancer community and encourage alignment and, ultimately, ensure its impact.

*The who, what, when, where, why and how of the cancer plan needs to be better marketed.*

Confidence in the impact of the plan can be established through better communication.

*Knowing that it will help move cancer related activities forward in Colorado. Seeing and learning about...where impacts have been made through the use of the cancer plan in the past and intended actions and participants moving forward.*

All members of the cancer community need to feel welcome at the table.

*Being invited to meetings or included in emails to know what is taking place regarding the Colorado Cancer Plan.*

### Workgroups should be flexible and may need to be organized in multiple ways.

While slightly more than half of respondents (54%, n=103) indicated that workgroups should be organized along the cancer continuum, there were noted concerns about potentially losing buy-in from cancer-type experts.

*I think organizing work around the continuum of care makes sense, however, we need to ensure that the "body part" special interest groups do not become disenfranchised. It must be made clear how they fit and how they will contribute while still maintaining their passion around specific cancer types.*

*It is nice to align all cancer types by the phases listed, but there are areas specific to each disease type that will impact these areas (ie: screening has been shown to be less than effective in certain disease types.) Prevention (areas like diet and exercise)*

*can be important for all disease types, but prevention of colorectal cancer (by colonoscopy) is unique to that disease. At the university level, oncologists are often specialized by disease type (though some disciplines overlap, ie: surgery/palliative care.)*

*I'm torn. I think you will get better buy in from npos/community organizations if it's organized by cancer type, but I think organizing by continuum of care will bring better collaboration and just makes more sense now that it's organized that way.*

Several respondents commented that a hybrid of the continuum and cancer type structures may be necessary to ensure involvement of cancer-type experts and successful collaborations.

*Both - work groups along the cancer continuum of care should address all-cancer objectives while work groups for cancer types should implement disease-specific nuances in implementation.*

*If organized by continuum of care, it seems there will also be a need for subgroups organized by diagnosis.*

## CONCLUSION

Members of the Colorado cancer community are passionate about their work and highly value collaborative efforts to address cancer. The Cancer Plan can be a valuable tool for stakeholder engagement and can fuel collaborative efforts, but there is a need for clarity about its purpose and value. Including the broader community in conversations about the plan to ensure it remains relevant to individual practice may be needed for widespread support. Increased communication and education—and having the right partners at the table—can help to bridge this divide.

CDPHE is in a natural position to guide the development of an organizational structure and continue in an administrative capacity to move the Cancer Plan forward. In that capacity, CDPHE should ensure that the leadership and direction of the plan itself is a collaborative effort among those individuals and organizations across the state with the expertise and capacity to ensure the plan's success.

CDPHE has engaged Strategic Health Concepts (SHC) to help facilitate the next steps. SHC's lengthy experience working with national and state cancer organizations and state cancer plan implementation efforts puts them in a good position to utilize these findings to guide upcoming conversations with stakeholders.

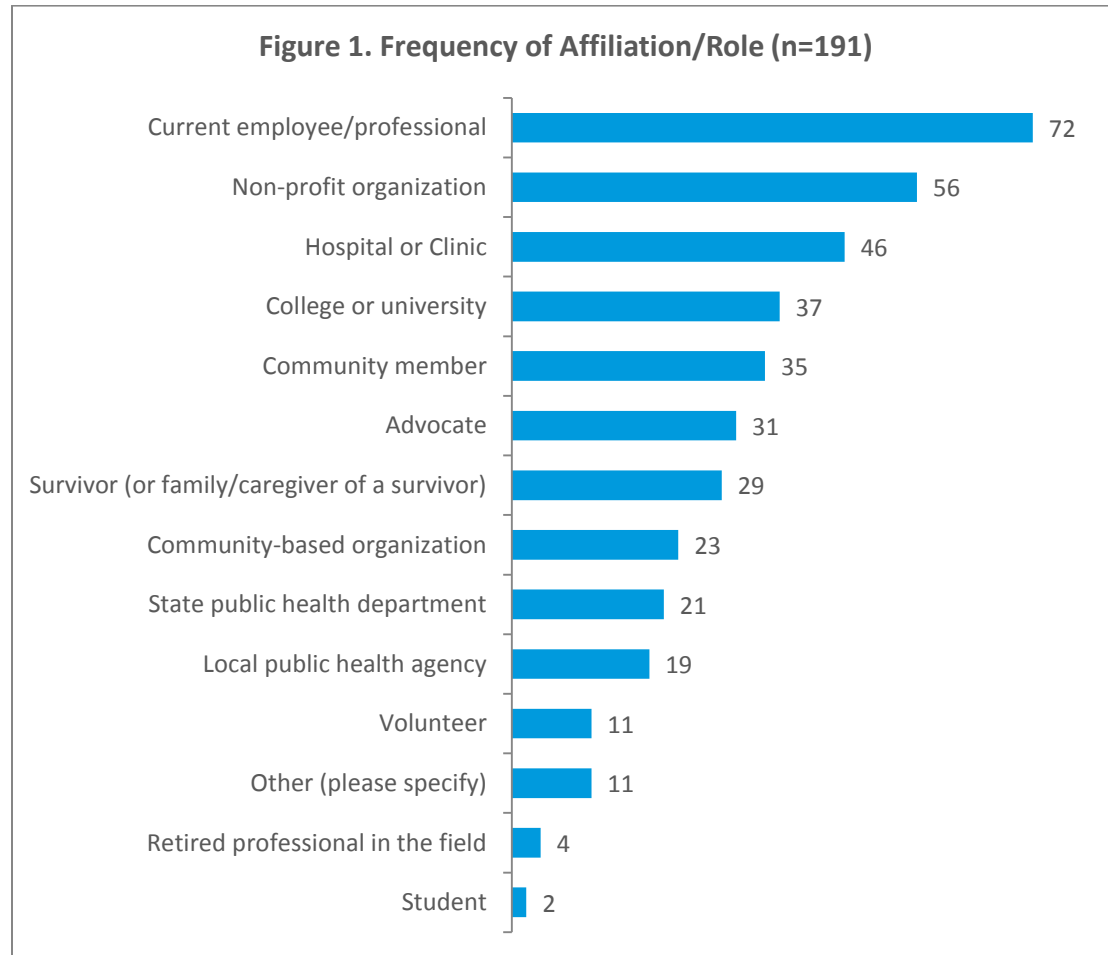
## APPENDIX: DATA SUMMARY

This section is organized by survey question. Only respondents who completed the survey (n=191) were included in the results. Questions 1-6, 10 and 13 were mandatory. All other questions were optional. For each question and table, *n* represents the total number of respondents. Frequencies indicate the number of responses, which may be greater than the number of respondents for those questions with a “Check all that apply” option. Open-ended responses, including comments, were coded and clustered to identify emerging themes where possible. In some cases, comments were shortened or eliminated to avoid identifying a respondent and only the most pertinent comments are included (e.g., duplicative comments were condensed and only a representative comment is included). Irrelevant comments, such as “I don’t know,” were excluded from this analysis.

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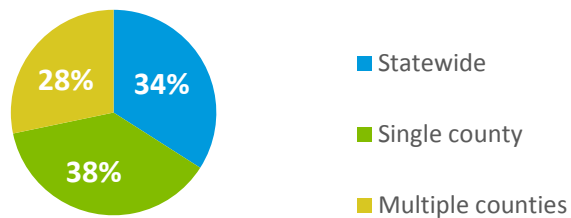
Question 1. Which of the following best describes your affiliation with the Colorado cancer community? (Choose all that apply)



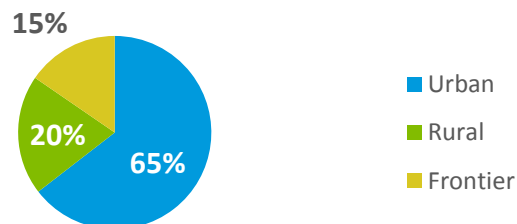
Respondents who selected “Other” primarily used the response space to further define roles in already-selected categories, e.g., “Foundation” “Nurse Navigator,” etc.

Question 2. Which of the following counties do you represent related to your involvement with the Colorado cancer community? (Choose all that apply)

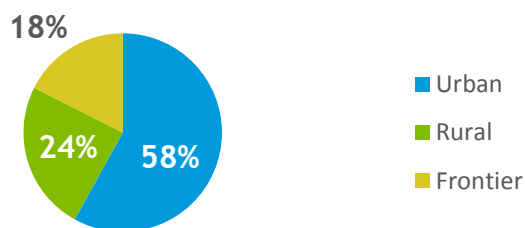
**Figure 2. Percentage of represented counties (n=191)**



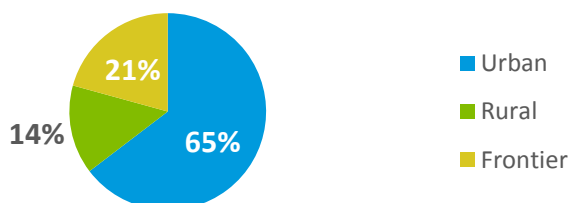
**Figure 3. Percentage of represented counties by type (n=127)**



**Figure 4. Percentage of single county representation, by region (n=72)**

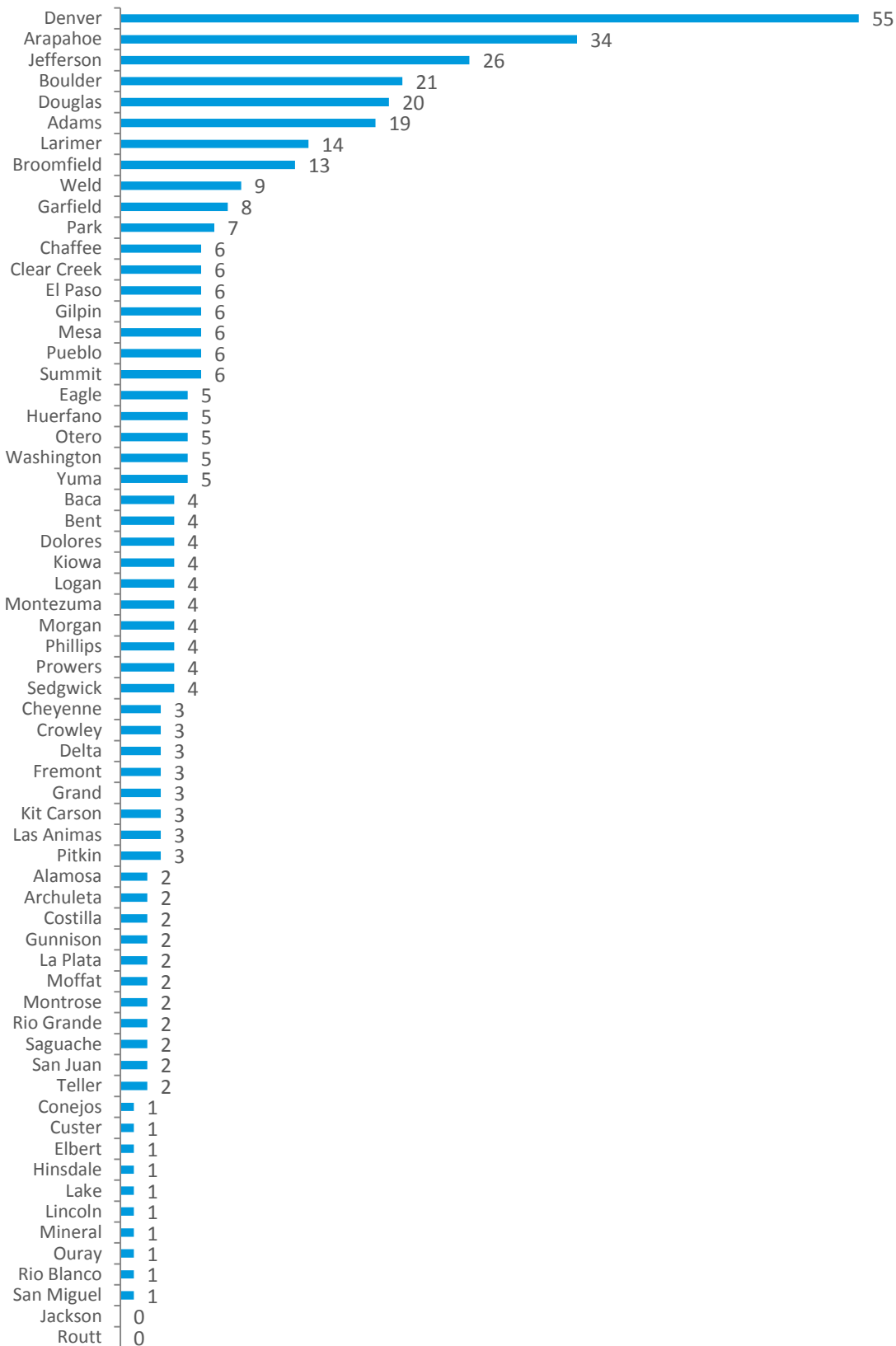


**Figure 5. Percentage of multiple county representation, by region (n=54)**

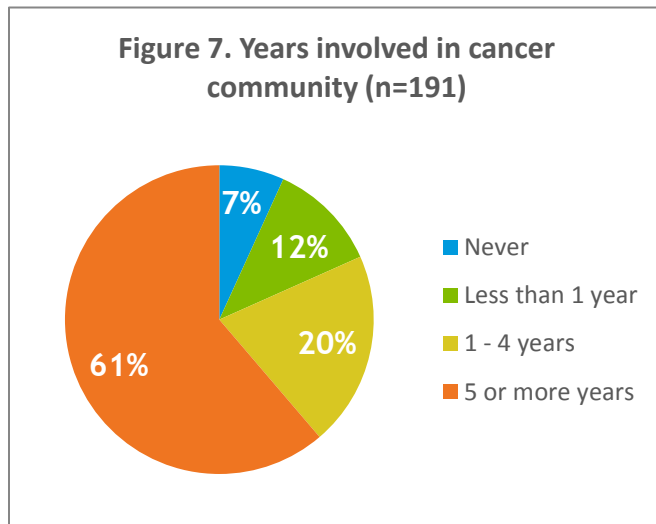




**Figure 6. Frequency of responses for counties represented (n=389)**



### Question 3. How long have you been involved in the Colorado cancer community?



#### Comments (n=13)

Several respondents commented on their long history of involvement:

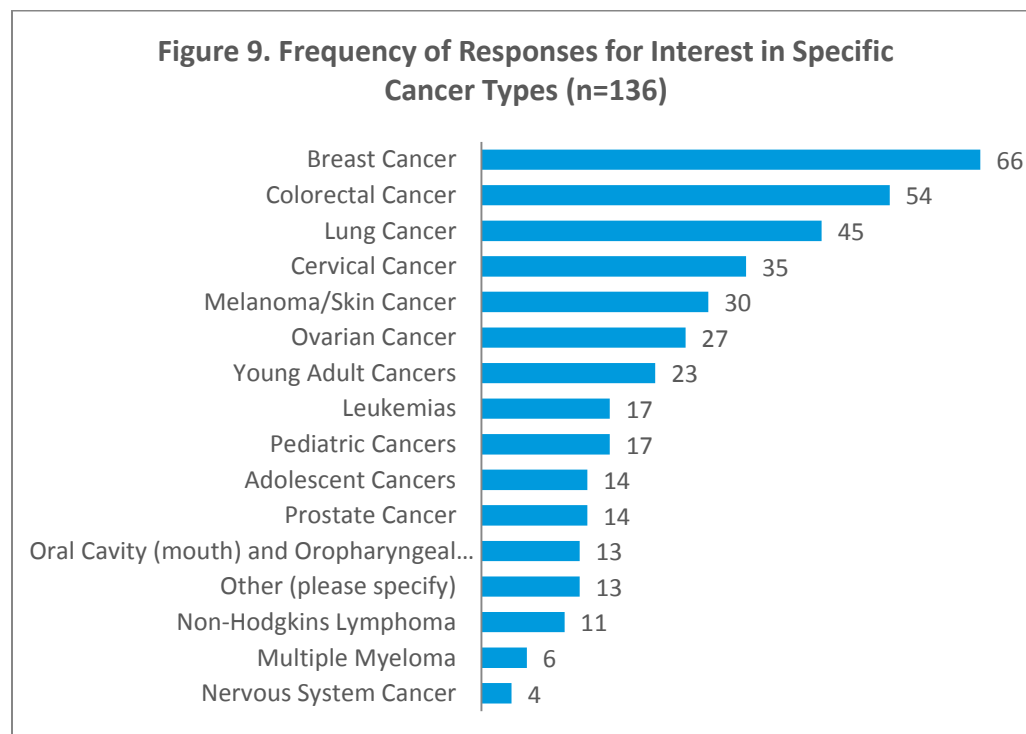
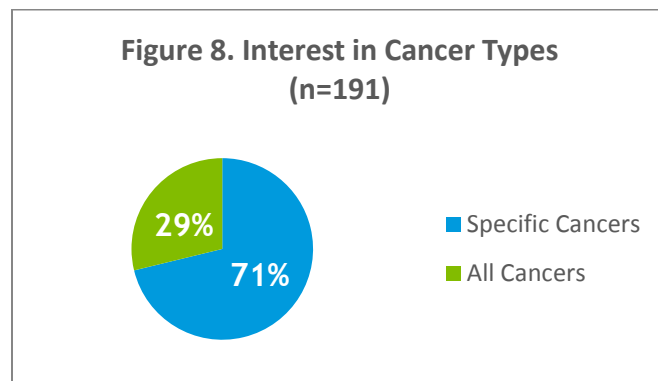
*Since 2000. I don't really represent any one county, as our Cancer Center serves anyone who can come here for treatment*

*Some of my Colorado family members and friends battled cancer as many as 20 years ago.*

*We have been doing primary care guideline development and quality improvement since 1996.*

*I have worked in public health for more than 20 years, and would consider myself involved in cancer prevention...[but] now I am a care giver of a cancer patient and feel much more involved in the cancer community.*

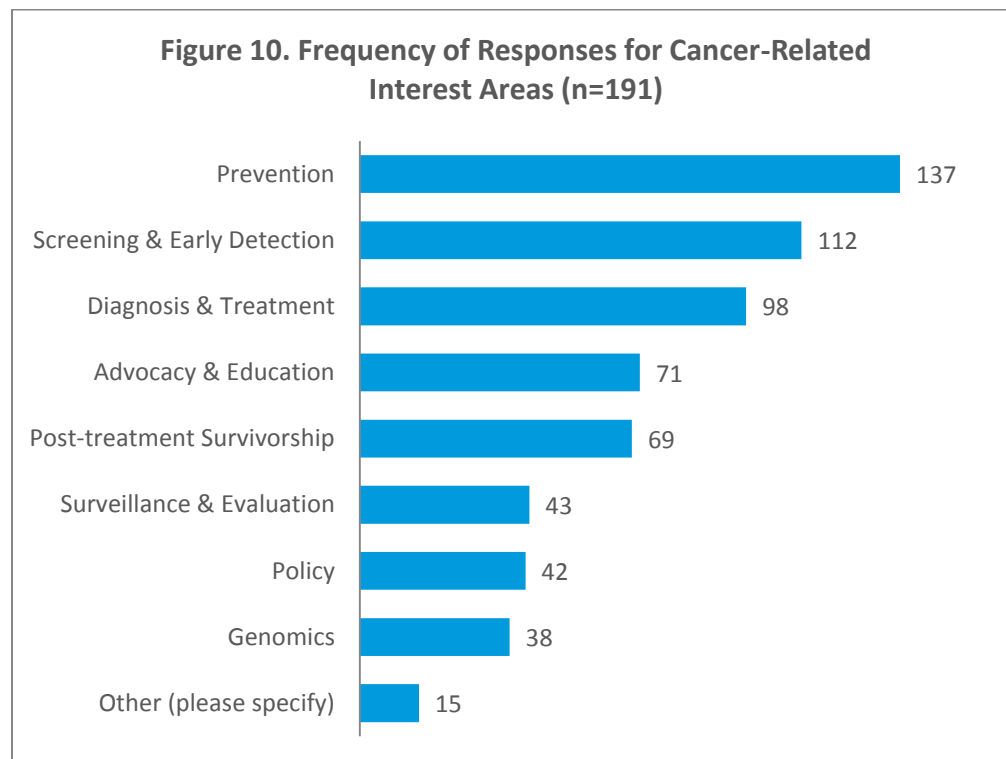
Question 4. What type(s) of cancer are you most involved or interested in? (Choose all that apply)



#### Comments (n=13)

- Adult only, all cancers
- All cancers as a negative health outcome linked to obesity
- All tobacco-related cancers, and cancers that disproportionately affect low-SES and behavioral health populations
- Basic cancer research in a biology lab
- Bile duct/pancreatic cancer
- Bone Marrow Transplantation
- Esophageal, gastric, pancreas, sarcoma
- Hereditary Cancers
- Most experience in breast cancer, but interest is in all
- Pancreatic
- Primarily adult cancers
- Thyroid, kidney, uterine
- Uterine cancers

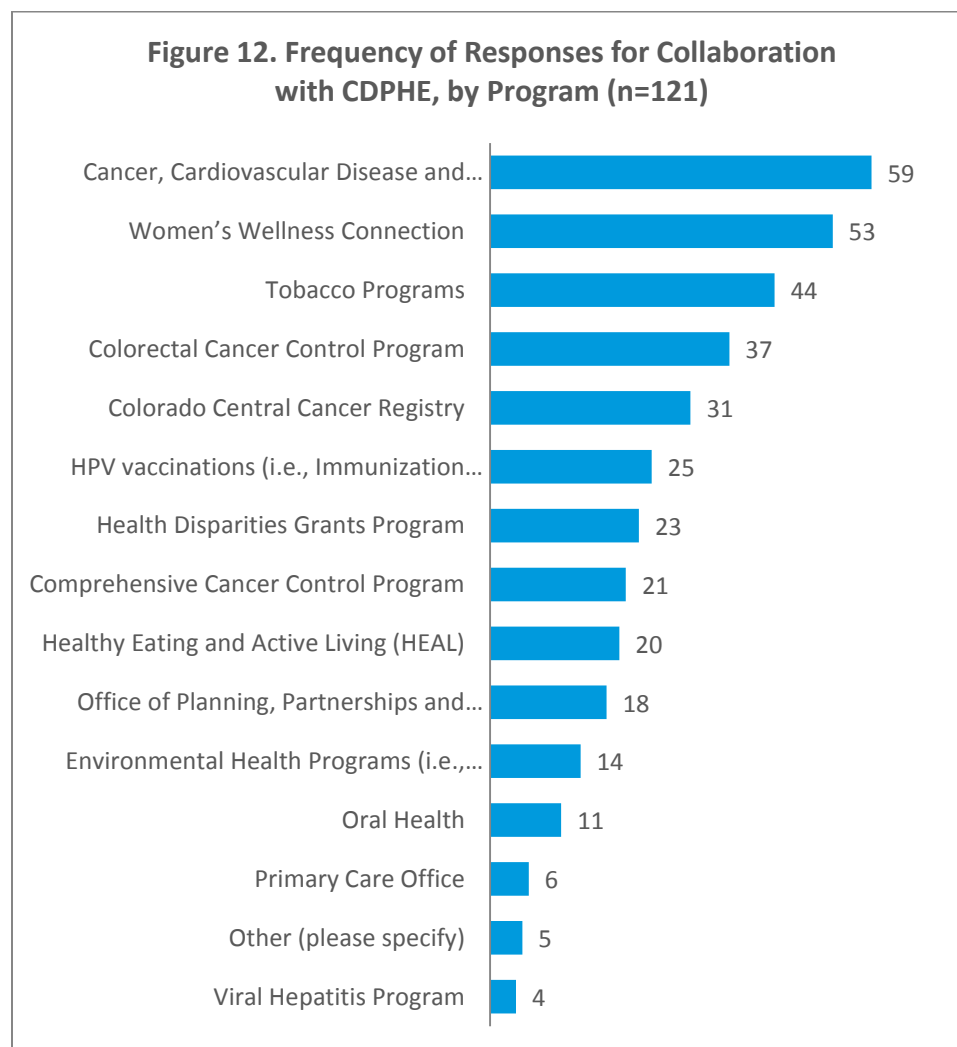
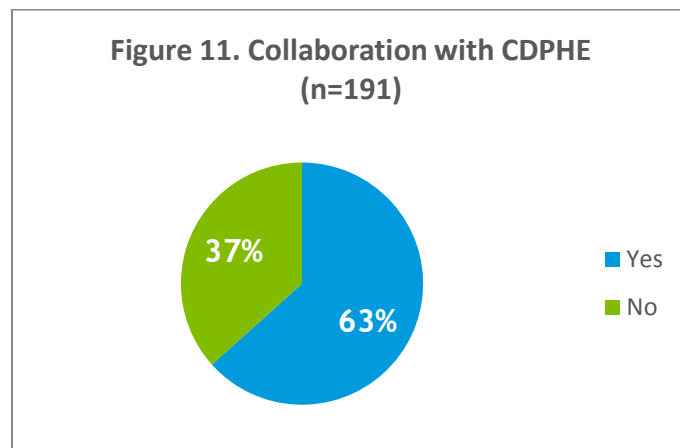
**Question 5. What cancer-related area(s) are you most involved or interested in? (Choose all that apply)**



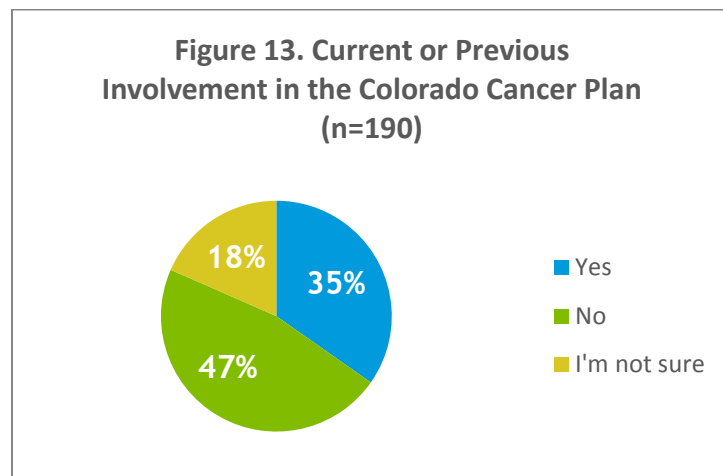
#### **Comments (n=15)**

Of those respondents who selected “Other,” 40% (n=6) commented that they were interested in research, 27% (n=4) were interested in palliative care/quality of life and 13% (n=2) expressed interest in funding. The remaining respondents (20%, n=3) were interested in health equity/rural health, resources or all areas.

**Question 6. Do you currently collaborate with any of the following CDPHE programs?  
(Choose all that apply)**



Question 7. Are you now or have you previously been involved with the Colorado Cancer Plan? (Choose one)



**Question 8. Please indicate how much you agree with each statement below related to the 2016-2020 Colorado Cancer Plan (n=189)**

Each answer is given a score ranging from 1 = strongly disagree to 5 = strongly agree.

**Table 1. Colorado Cancer Plan Perceptions and Intentions**

	n	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)	Rating Average
The Cancer Plan will facilitate measurable change and increased health outcomes.	188	3 2%	5 3%	61 32%	85 45%	34 18%	<b>3.76</b>
The Cancer Plan will enable me to leverage resources and partnerships for cancer-related activities.	188	3 2%	6 3%	63 34%	91 48%	25 13%	<b>3.69</b>
The Cancer Plan will allow me to impact cancer-related activities and priorities.	188	3 2%	6 3%	70 37%	83 44%	26 14%	<b>3.65</b>
The Cancer Plan will help me to stay informed of cancer related activities.	188	4 2%	9 5%	58 31%	100 53%	17 9%	<b>3.62</b>
I plan to align my cancer-related efforts to the Cancer Plan.	188	7 4%	9 5%	84 45%	64 34%	24 13%	<b>3.47</b>
I will be involved in the Cancer Plan because it is part of my job responsibility.	187	34 18%	28 15%	69 37%	43 23%	13 7%	<b>2.86</b>
I will be involved in the Cancer Plan because it is a requirement of a funder/grant.	185	35 19%	45 24%	77 42%	18 10%	10 5%	<b>2.58</b>

## Question 9. What would motivate you to get involved (or more involved) in the Colorado Cancer Plan?

### Comments (n=120)

Not all responses from this question are reported below. Comments represent the range of responses provided for each theme.

Respondents noted that their motivation for involvement was largely based on the relevance of the Cancer Plan to their work (n=40).

*Knowing that it has value or relevance to what I and our clinical team already do.*

*If there were logical linkages with my current work.*

*Understanding how the plan impacts our work.*

*Hopefully the new cancer plan will help the state prioritize mental health, behavioral change, prevention, and family (caregiver) wellness and provide funding for programs aimed at these issues. These are critical elements for a Colorado dealing respectfully and meaningfully with the reality of cancer even though the impact of such programs is often indirect and hard to measure. If the Plan does prioritize these efforts, our organization will naturally be operating in alignment with the plan.*

They also wanted to better understand the Plan on multiple levels, including strategies for incorporating the Plan into the work they do.

*To make it more useful to me in my work than it has been in the past and to better understand how to incorporate it into the work I would like to be doing.*

*Having it be practical, with easy to implement goals.*

Many wanted to fully understand how the Plan would have greater impact on cancer.

*Just seeing how this plan will be put into action and all the different ways we can make it successful. I think it's hard sometimes to make the connection between putting it on paper and how we will actually make a difference with the plan.*

*Knowing that it will help move cancer related activities forward in Colorado. Seeing and learning about...where impacts have been made through the use of the cancer plan in the past and intended actions and participants moving forward.*

*I think the Cancer plan, if done in the right way, can impact the outcome of cancer diagnosis, either through early detection or prevention.*

*The ability to make a difference in diagnosis/treatment of cancer for those who are uninsured or underinsured.*



Several respondents pointed out that they or their colleagues were unfamiliar with the Plan and would need to better understand it (n=37). Increased awareness—through clear articulation of the plan itself as well as effective communication—may motivate more participation and adherence to strategies.

*Few of my colleagues even know it exists; none have ever found it necessary to review.*

*Understanding what it is and how it would effect/help my program.*

*Knowing how it benefits patients and more details about what it actually is.*

*I have never heard of it, so active outreach related to potential collaborations would be helpful.*

*The who, what, when, where, why and how of the cancer plan needs to be better marketed.*

*A "launch" of the cancer plan with statewide stakeholders*

*An easy to use/navigate document that allows me to search just for the items/areas I am most interested in.*

While many respondents indicated that they had very limited time or resources (n=23), some also wanted clarity about how they could be involved.

*A clear understanding of what involvement would require. There is currently scarcely an extra minute in my day; yet I'm interested in incorporating the Colorado Cancer Plan's objectives in my work.*

*Having a clear idea of what I could [do] that would help.*

*More defined role for rural partners.*

*Simple more directed process with clear expectations.*

Some suggested that the process around developing and implementing the Plan offered opportunities to increase involvement, particularly around collaboration (n=9).

*Continuous collaboration! Monthly meetings and FOLLOW-THROUGH*

*Getting to know the people at CDPHE that will coordinate it.*

*Better connections with community based organization (not just clinics, hospitals and large research organizations) and indications that the role of community based organizations are valued and supported in their role.*

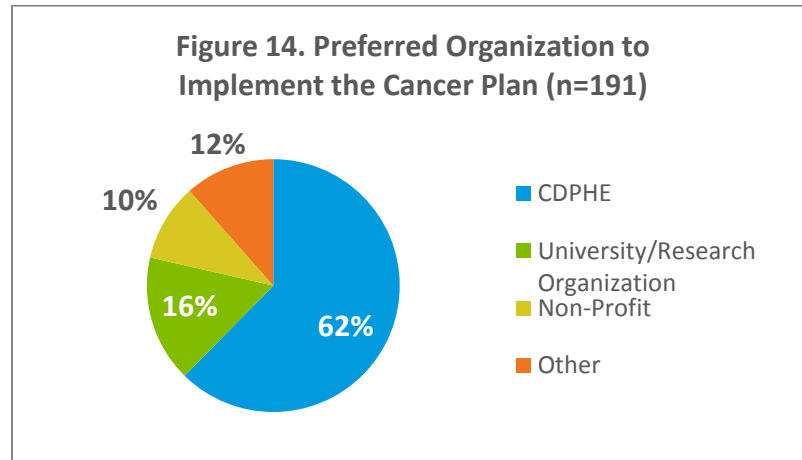
*An online community that makes it easy to see progress on the plan and connect with people working on similar projects or goals.*

*Having statewide involvement, more buy in from rural communities.*

*If there was a mechanism for more interaction between the cancer task forces to coordinate common interests.*

*An active community of people who are engaged in the tasks of the plan. Working with others on common goals.*

**Question 10. What type of organization should take the lead role in facilitating the implementation of the Colorado Cancer Plan? (Choose one)**



**Comments (n=50)**

Many respondents envisioned the Colorado Cancer Plan as a collaborative effort (n=11).

*I believe this is a multi-level task with many branches of support needed. Due to funding and support this should be split between State and Non-Profit in an effort to work on promoting effective team collaboration to reach the highest impact.*

*Seems that suggested groups all could have vested interests in implementation of such a plan. I would therefore suggest a new group composed of equal representation from above groups and stronger representation from cancer survivors in equal proportion to proportion to occurrences of each type of cancer. I believe group should be led by a survivor. They have the most "pure" vested interest in seeing this plan work.*

*The State Health Department should be able to convene the organizations that should be involved and also understand the nuances for getting the plan to the point of implementation. At that point have the community actually implement it.*

*As public agencies, the state department of public health and the University of Colorado are limited in their ability to implement/pursue public policy changes that can remove some barriers to cancer care. An independent non-profit organization should take the lead on coordinating and aggressively developing/implementing legislative and regulatory plan to remove systemic barriers to cancer care. A university/research organization doesn't reflect the true needs & barriers of all Coloradans attempting to seek cancer care so is not ideally positioned to implement the cancer plan. The state department of public health or a university/research organization may be best positioned to act as a convener and to hold other partners accountable for implementation.*

*The task force volunteers do a lot of the work but the health department is ideal for leading the effort and pulling it all together.*

*The state should strongly facilitate (not lead), and work closely with community partners to accomplish the cancer plan goals and objectives.*

Some commented that the State, which receives federal funding to develop and implement the Plan, should play a key role in that process (n=10).

*The state department of health has a mandate to promote and protect the health of all Coloradans. While working with everyone is necessary the state should not defer leadership roles to other organizations. They should make this a priority.*

*CDPHE seems to have a meta-analysis view and access to State Registry data and policy developments related to cancer care.*

*Development and implementation of the cancer plan is CDPHE's responsibility to CDC, so it makes sense to me that CDPHE should have control over moving the work forward.*

*CDPHE has a vested interest in the project, statewide reach, experience with action planning and evaluation capacity, not to mention can align the effort with other statewide plans and efforts. However, if there are other groups that have a vested interest, similar reach, strong facilitation skills, and positive relationships with a variety of stakeholders, those groups might also be a good fit for implementation.*

*In my experience in the past 20 years, the state has the structure to connect with many agencies. The university does not have infrastructure nor mission to connect with the many agencies and institutions connected to the cancer plan.*

One respondent noted that the health department plays an important role in providing consumers a means to contribute:

*Needs to include the consumer input... Taxpayer dollars should support health plans for the state, not local foundations, etc., that have the ability to drive the directions of nonprofits and policy makers. The Health Department has legislative oversight and the governor appoints director of agency so this gives consumers a pathway for input (legislators) in addition to the Board of Health.*

One respondent expressed concern that the state has a limited perspective:

*No offense to the state, but government agencies care too much about the immediately available measurable results of programming regardless of whether such programs have any lasting, sustainable and meaningful effect.*

A few respondents (n=5) felt that non-profit ties to the community and flexible structure would be beneficial to implementing the Plan.

*Non-Profits are already adept at gathering stakeholders into work groups and have more flexibility/less red tape than State and University staff.*

*The plan can be written by whomever... but it should be implemented by a non-profit, with ties to the community.*

*Colorado Cancer Coalition.*

*A governing group of nonprofits that have nothing to gain.*

A few respondents also commented that universities had the resources and expertise to implement the Plan (n=3).

*The worlds of cancer treatment, cure, and continuum of care implementation is ever changing and universities, by design, are more aware of and more responsive to such changes. The state can provide valuable oversight, support, and funding, but in general the implementation should be run in partnership with universities, hospitals, and other research orgs with universities in the central seat.*

*Research Universities are major stakeholders and have a great deal of incentive (Funding and teaching opportunities) to remain active participants and keep the State moving forward to accomplish initiatives in the Cancer Plan.*

*A research entity is equipped with the expertise to conduct Cancer related (across the spectrum) implementation and evaluation of cancer related programs and initiatives.*

One respondent expressed concern about the limitations of a university:

*Not a University. While well-intentioned, there tends to be an unrealistic, academic slant to their projects that does not work well in smaller, rural communities.*

Six respondents were uncertain about the entity to take the lead role in implementing the Cancer Plan:

*Probably depends on who is held responsible to meet the goals/metrics of this plan at a high level and what the funding stakeholders want for control knobs.*

*Whoever has the funding/resources to ensure it is done and done well.*

*Realizing most of the input is coming voluntarily, it's pertinent to meet deadlines and maintain accountability on all task forces who participate.*

*Non-partisan no conflict of interest has resources.*

**Question 11. What role should the Colorado Department of Public Health and Environment (CDPHE) have in implementing the Colorado Cancer Plan? (n=44\*)**

Only those respondents who did not select CDPHE in Q10 (n=72) were directed to this question. Of those, 61% (n=44) provided a relevant response.

Most respondents (n=34) valued the involvement of CDPHE as a strong, active partner in the Colorado Cancer Plan in myriad ways.

*Lead the effort in getting a solid, committed team on board to finalize the Plan and have them ensure that there is STATEWIDE buy in.*

*Ultimately the leadership role, but with other types of organizations on the leadership committee.*

*Identifying a few critical components and ensuring some CDPHE work targets those activities. Also, Whether CDPHE does this or whatever organizational structure houses the plan ~ it would be nice to see some identification of where some of the objectives are being worked how that are being approached and down the road ~ measures of impact. Who is doing what and where...as it relates to the plan objectives.*

*They definitely need to be a strong partner in the process.*

*They should oversee measurable outcomes.*

Despite this desire for state involvement, there was some concern about the state's limitations:

*I believe the CDPHE has a requirement to develop and help implement the Colorado Cancer Plan. I think this is an important role for CDPHE and it seems that sometimes the CDPHE staff get spread so thin or change positions too often to be able to have consistency in the effort. I could be wrong about this but it is my sense.*

Some viewed CDPHE in a primarily administrative or support role.

*I think they should function as a coordinating center.*

*...CDPHE can organize a talk where people from all aspects (clinicians, basic researchers, cancer survivors and potential donors) could meet and discuss strategies for cancer control.*

*Help facilitate conversations, get people focused and working and enable the community partners, through funding and resourcing to get the work done. Evaluate.*

*Support, staffing, information, access to resources such as data, training, assisting the task forces in carrying out the tasks, funding if that is possible.*

Several respondents noted that CDPHE should take responsibility for information dissemination:

*To make sure information and availability is correct. No one is given false information.*

*Support the work groups putting together the plan and get the word out when it's time to implement.*

*Dissemination of information, opportunities, research collaborations, and similar.*

*Primary role of developing it and disseminating it out to the appropriate recipients.*

A few respondents commented that CDPHE should act as a policy advocate or regulatory body.

*Advocacy of cancer-related policies; allocation and award of Amendment 35 funds in alignment with the Plan; implementation of programs specifically designated to CDPHE by the coalition.*

*Aid in raising cigarette excise tax, implementing access of lung cancer screening for all appropriate patients. Implement strong anti-tobacco campaign for youth, and quitting program for adults.*

*They should oversee the governing body and regulate the hospitals.*

Some respondents thought that CPHE should focus on funding in some capacity (n=10).

*Funding, oversight, and aligning resources for the greatest impact. The state may have to take a more active role in ensuring that adequate funding makes its way to designated "hot spots" and rural areas--areas that due to intellectual and human capital deficiencies might find it difficult to otherwise appear qualified to accept funding.*

*CDPHE should use its extensive funding and data.*

*Funding and ability to incorporate solid plans of action into state legislature or positive change promoted by state agencies.*

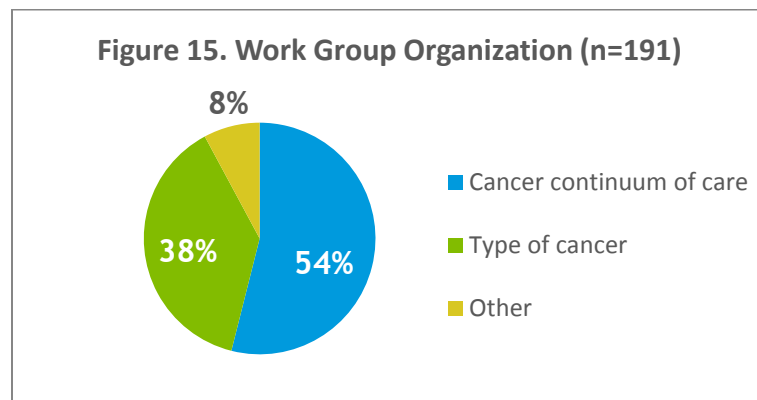
**Question 12. When thinking about the most qualified leaders in Colorado's cancer community, who would you recommend to help implement the Cancer Plan? Please list specific names and affiliation, if possible. (n=74)**

Respondents listed several individuals (names/affiliations removed to protect privacy) and suggested including a wide array of public and private organizations and individuals to ensure a “multidisciplinary approach,” including (but not limited to): hospitals, cancer centers and specialists, universities and research organizations, nonprofits, advocacy/fundraising entities, foundations, survivors/family members, community organizations, professional associations, economists, epidemiologists and providers.

*Needs to include economist, epidemiologists, consumers, and licensed health experts. They are all policy makers so do not need formal policy-maker such as legislators, as they often silence others.*

*Before we answer this question, I think we really need to figure out the top management level structures of this plan & the leadership skills, the passion, the past success record, roles & responsibilities, and accountability.*

Question 13. When thinking about implementing the Cancer Plan, how would you recommend that work groups be structured? (Choose one)



### Comments (n=23)

Though most respondents to the survey question indicated that they thought work groups should be organized by the cancer continuum of care, most of those who commented (n=15) suggested some combination might be necessary.

*Both - work groups along the cancer continuum of care should address all-cancer objectives while work groups for cancer types should implement disease-specific nuances in implementation.*

*Both. Work groups can provide the guide for the continuum of care to providers, while more emphasis on specific types of cancer would help the patient more.*

*By focusing on the continuum of care, setting a system in place, it could be applied to all forms of cancer, setting a standard.*

*In general, our organization prioritizes continuum-of-care model with an emphasis on prevention and behavior change related to self-monitoring and self-care. This general approach spans across cancers. However, to the extent that some interventions must be cancer-specific and different cancers have distinct courses, some specialized knowledge of specific cancers will be required to execute plan priorities and provide sufficient funding in the right areas. Thus a blended approach is probably necessary.*

*First, people will never break out of their own specific organizational box if it is done by type of cancer. It will be difficult enough by continuum phase, but easier, I think as it will force people to think outside the disease set in which they are involved. I also recommend mixing them up. For example, a leader is a leader. If you select someone who currently works primarily in detection, ask them to work in a different phase.*

*I'm torn. I think you will get better buy in from NPOs/community organizations if it's organized by cancer type, but I think organizing by continuum of care will bring better collaboration and just makes more sense now that it's organized that way.*

*It is nice to align all cancer types by the phases listed, but there are areas specific to each disease type that will impact these areas (i.e.: screening has been shown to be less than effective in certain disease types.) Prevention (areas like diet and exercise) can be important for all disease types, but prevention of colorectal cancer (by colonoscopy) is unique to that disease. At the university level, oncologists are often specialized by disease type (though some disciplines overlap, i.e.: surgery/palliative care.)*



Much of the reasoning for a blended structure had to do with the need to mirror how people work and ensuring that specialists with the necessary content knowledge were included.

*I'd like to see it structured by phase ~ but realistically, people often associate and put work effort in by type of cancer. There may be many situations where, if structured by phase, there may not be sufficient knowledge of multiple (or all) cancers represented. UNLESS, work groups are structured by phase and ensure there is representation of all cancer types in the work group.*

*...I think one reality of cancer activities today is that they are focused on specific types of care across the continuum, and asking someone who is invested in one specific cancer area to potentially have to participate on multiple work groups to stay involved goes against the grain a bit. Either way (organizing by phases or type of cancer) means you will need to meaningfully plan to integrate activities in the other way as well (i.e. if organized by phases, have a plan for keeping participants who want to be meaningfully involved across the continuum for a specific cancer, and vice versa).*

*I think organizing work around the continuum of care makes sense; however, we need to ensure that the "body part" special interest groups do not become disenfranchised. It must be made clear how they fit and how they will contribute while still maintaining their passion around specific cancer types.*

*While I think the groups should be organized along the cancer continuum, I think this will take a while to shift people's paradigm.*

Some expressed concern about structuring work groups only by the continuum:

*For me personally and for many sub specialist clinicians, it would be hard to get involved in a more diffuse group than those dealing with your organ system. I can see where ACS and CDPHE staff and perhaps primary care providers might feel comfortable with the cancer care continuum approach, but any of the specialists would likely not feel the same.*

*Many individuals are drawn to this work b/c of personal experience with a specific type of cancer. Also, some cancers, such as pediatric, are very different in terms of the continuum and require either personal or professional experience in order to be able to contribute relevant input.*

*There are fewer phases of cancer care, making the work groups too large and diluted in their efforts. Most of the cancer information and research seems to be organized by cancer type and treatments. And, not all phases of cancer care apply to each type of cancer.*

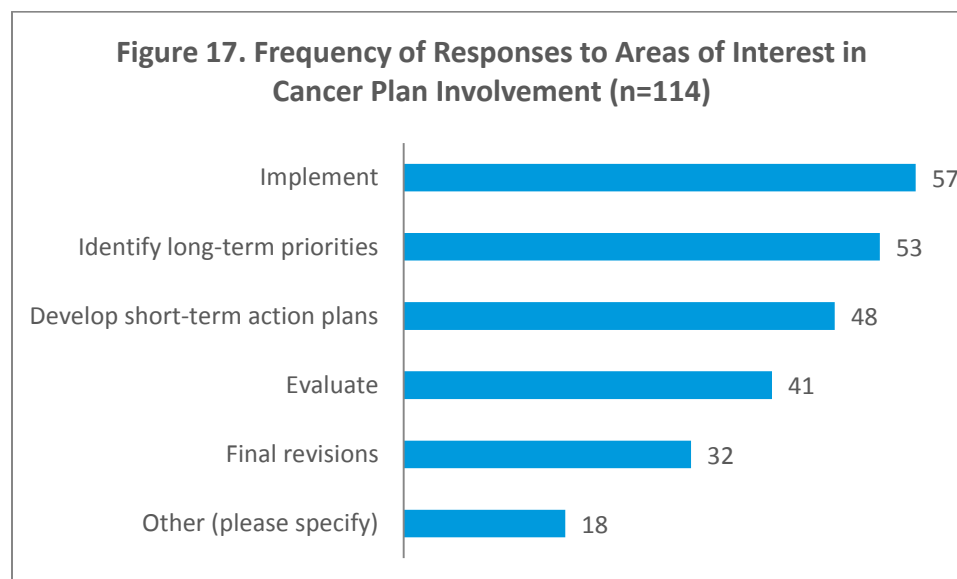
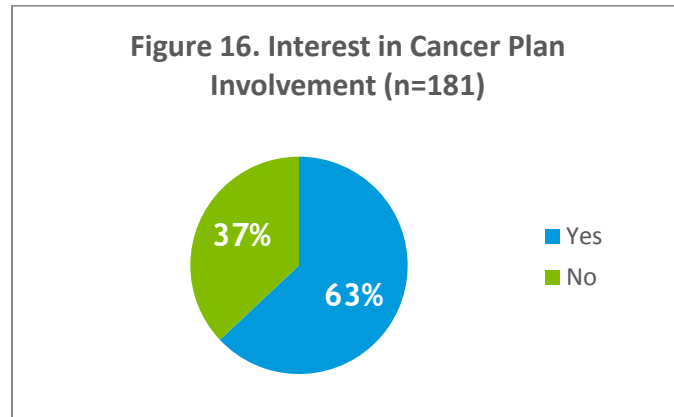
Others noted additional challenges or suggestions:

*Step back to take a holistic view. Look at the causes of cancer. Determine how causes can be tackled for prevention, management, and treatment using both conventional and integrative approaches since ~87% of cancer patients use some form of complementary and alternative medicine (CUSF cancer survey of CU patients). Also break down groups for various cancers. However, there needs to be cross-communication forums so one group sees the other groups' work.*

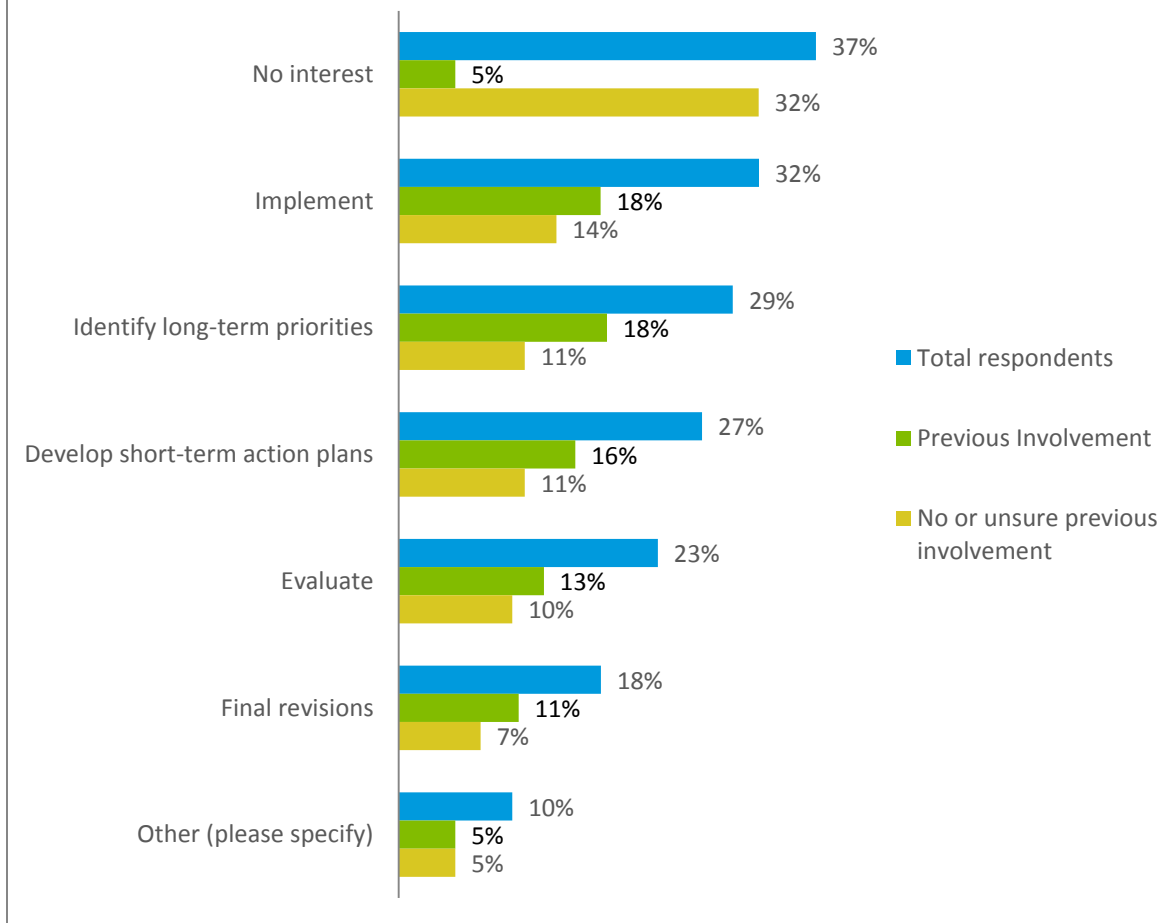
*Work groups should focus first on the individual and how to direct to appropriate care.*

*Age specifications which result from studies and current state programs should be noted: Neonatal/prenatal/infancy, pediatric school age, Adolescent, Young Adult, Adult, Elderly/Geriatric these populations may share many types of cancer or different types, but resources funding and SUPPORT should be equal!*

Question 14. Would you like to be involved in the Cancer Plan in any of the following ways? (Choose all that apply)



**Figure 18. Percentage of Responses to Interest in Future Involvement by Previous Involvement in the Cancer Plan (n=180\*)**



\*One respondent was excluded from the cross-tabulation of Questions 7 & 14 due to incomplete responses.

### Comments (n=14)

Respondents expressed general interest (n=8) as well as specific interest areas (n=6).

*I am interested in gathering more information and help where I'm best suited*

*I would like to assist in any way I can be of help (without overcommitting :-)*

*Perhaps examining dissemination of the plan in public health practice and settings*

*I am interested in having integrative medicine added to the Colorado Cancer Plan & its implementation in terms of education and research*

*I am interesting in working on a specific chapter of the Cancer Plan - Melanoma/Skin Cancer - and its objectives.*

*Advisory levels, input on water related issues*

*Ovarian cancer task force*

**Question 15. Do you have any additional comments or feedback regarding leadership or implementation of the 2016-2020 Colorado Cancer Plan? If not, leave blank. (n=9)**

Nine respondents offered additional feedback. Three of those mentioned the need to ensure that the right stakeholders were at the table.

*My preference would be to work with a small-ish group of dedicated people who are focused on moving the needle on cancer in the state.*

*The most important part is the implementing programs and follow up to get the desired outcome, less chiefs and more indians.*

*No, except remember this is not about politics or geographical representation--it is about expertise and experience.*

Some noted the importance of clear and consistent communication related to the Cancer Plan:

*The Cancer Plan process feels especially confusing this year, given that the goals are based on the continuum of care, but the work groups are still primarily cancer type.*

*This plan needs to be reachable for everyone and to be in simple language to be easily understood.*

Two respondents reiterated the importance of the Plan, including the need for adequate support for implementation.

*The Cancer Plan is a valuable resource for the state and also provides a motivation for clinicians, researchers, businesses, and community members to coalesce around a common goal.*

*I think it's important to make sure that there is as much resource put forth to make sure this effort is done.*